The Office of Minority Health, U.S. Department of Health and Human Services

Rapid Assessment, Response, and Evaluation (RARE) Program Final Evaluation Report

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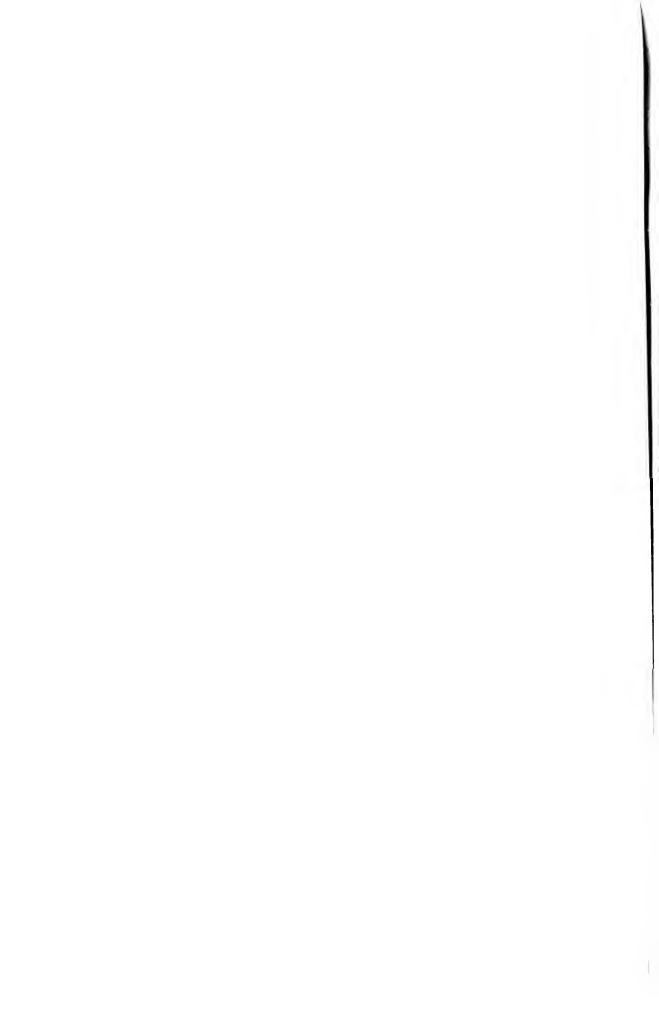Cathleen Crain, M.A., Project Monitor

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Acknowledgements

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I. Executive Summary

The Rapid Assessment, Response, and Evaluation (RARE) process, from which the RARE Program was developed, uses mixed social science methods to produce quantitative and qualitative population assessment data useful in planning for and implementing HIV/AIDS prevention and services. The RARE Program, under the Office of Minority Health (OMH/DHHS), provided funds to local projects to implement the RARE assessment.

This evaluation report examines the applications of RARE assessments in 63 cities based on a systematic analysis of available final project reports and other materials from grantees. The OMH RARE Program has funded two cohorts of grantees. Cohort 1 grantees were local public health departments and selected community-based organizations (CBOs). Cohort 2 was comprised of CBOs focusing on underserved populations, including minority women and the relationship of Intimate Partner Violence (IPV) to HIV among women.

All grantees used each of the *research methods* recommended by the RARE guidelines: direct observation, mapping, street intercept surveys, focus groups, and interviews with key informants. All sites endeavored to gather data from members both of the at-risk populations of focus and of significant figures in the larger community, such as HIV and other health and social service providers; community leaders of various kinds, including religious leaders and other stakeholders; local business people; and local government officials.

Grantees' *findings* identified a range of challenges to reducing the spread of HIV in the targeted populations and improving treatment and care. Prominent among these was the fact that high risk behaviors take place in a wide variety of fluid and overlapping social networks. These shifting networks link people who regularly engage in high risk behaviors with people who do so only rarely, often without having any knowledge of the potential risks.

Lack of awareness of risk is also a major challenge. Some individuals appear to engage in denial and fatalistic thinking with regard to risk, and do not appear to respond to conventional outreach methods focused on changing behavior through providing accurate information. Stigma, secrecy, and fear of public exposure also discourage people who engage in high risk behavior from seeking HIV testing or counseling, or substance abuse treatment.

Other social factors, such as patriarchal relationships and IPV, prevent some women who are at risk from successfully negotiating safer sexual encounters. In addition, many grantees observed considerable mistrust of public institutions, whose traditional approach to outreach and services has, in some cases, unintentionally perpetuated issues of stigma.

Grantees recognize that addressing these challenges requires enhancing and expanding services and eliciting the support of community leaders and institutions to combat stigma, promote awareness of risk behavior, and facilitate access to services. Religious institutions have a potentially positive role to play, although many have yet to address the issue constructively. Expansion and promotion of community awareness must be tailored to local community settings and must be flexible enough to adapt to changing social networks.

Grantees offer many *recommendations* regarding highly site-specific matters, such as designing educational messages to address the needs of a particular local group, including representatives of specified local populations, in planning and implementing outreach activities; clearing abandoned buildings in a specific neighborhood; or collaborating with particular local agencies and organizations. Many grantees, however, also invoke broader themes by emphasizing the importance of various forms of collaboration, integration, and inclusion in initiatives to address HIV/AIDS in their cities and neighborhoods.

Grantees also point out the wisdom of building on existing initiatives rather than, as so many put it, "reinventing the wheel." A few also strongly recommended careful monitoring and evaluation of all initiatives from start to finish, including establishing baselines prior to beginning implementation. Evaluation is a key component of the full RARE process.

Many grantees articulated interest in *future use of RARE methods* as part of local planning processes. Only a very few, however, reported that any local entity had formally adopted the method at the time of their final project report. Nevertheless, building and strengthening collaboration and cooperation among stakeholders is one of the most common themes in grantees' recommendations. It is clear that, in a number of sites, using RARE has at least nurtured the potential for the kinds of collaboration most grantees see as necessary for more effective action against HIV/AIDS.

Most grantees did not have the opportunity to develop *planning* processes within the RARE Program funding timeframe. Many did not explicitly discuss planning, but their recommendations suggested that RARE findings would be incorporated in planning. Many other grantees, however, particularly those in Cohort 2, did discuss steps to enhance the potential for incorporation of their findings into the local planning process.

Many grantees identified recruiting project partners and obtaining local cooperation in data gathering as *challenges to implementing RARE*. For instance, some grantees reported difficulty successfully engaging the interest of certain policymakers, public health agencies, or representatives from the religious community. Many grantees also had mild to severe difficulty obtaining cooperation in data gathering from potential key informants, cultural experts,

and focus group members because of scheduling problems and underlying lack of understanding or mistrust. Grantees, however, often overcame such challenges through vigorous cultivation of local networks.

RARE personnel in several sites also were challenged to accommodate the tight timeline of the RARE data collection and analysis process, a maximum of 4 months. Most grantees reported that they relied on flexible scheduling and staff dedication to complete the RARE assessment, but that they would have preferred additional time from initiation to reporting to ensure that their assessment was complete.

Grantees also identified an inherent tension in the RARE method between the value of including diverse segments of the community in all phases of the RARE process and the value of quickly obtaining quality data on often overlooked aspects of the local dynamics of HIV/AIDS. Inclusion can pave the way to otherwise inaccessible data and help mobilize longer-term community involvement and organization, but lack of local experience with data gathering and analysis was often cited as an obstacle to obtaining quality data rapidly. Managing this tension has two dimensions: the need to balance these two RARE imperatives in RARE training; and, as some grantees suggested, continuous monitoring of data quality and project schedules within local RARE teams.

Local RARE Projects findings and recommendations have *policy and program implications* for helping communities build capacity and develop effective strategies for assessing, planning, and implementing new or improved HIV/AIDS services. These fall into several interrelated categories, detailed below.

Structural Factors Affecting Access to Care
The following policy and programmatic implications related to structural access to services were reflected in the RARE grantee reports.

- More interagency collaboration could enhance the efficient and effective networking of services.
- Collaborative planning and coordination efforts on the part of service providers, including input from all stakeholders, could help define and promote linkages among providers and other stakeholders, and help them to recognize and begin to address gaps.
- Programs could emphasize marketing and advertising their services to ensure that the locations of existing services are known in the community.
- Mapping, and publicizing available services, locations, hours, costs, and transportation options could improve access.
- Colocating HIV, health, community, and social services could assist in facilitating structural and geographic access.
- No-cost testing could eliminate a commonly cited barrier to accessing HIV and AIDS care.

- Members of the local community could be used to staff services or as volunteers.
- Soliciting advice from clients regarding what services are missing, are not known to be available, or are difficult to reach could inform planning regarding service expansion and locations.
- Eliminating unnecessary duplication of services could create new provider opportunities and provide a wider array of services.

Cultural Factors Affecting Access to HIV/AIDS Services
Policies and programs should reinforce the importance of culturally accessible care, including providing language access and recruiting staff who have cultural competence relative to the community.

Access to HIV/AIDS Education and Information
Policymakers, providers, stakeholders, and consumers need improved understanding of HIV/AIDS and how it is affecting communities. Special attention should be paid to women and minorities, who often perceive current education and care efforts as excluding them. Education cannot assume people (including providers) have knowledge of the fundamentals of HIV/AIDS prevention. New and updated information should be disseminated regularly.

Stigma and Discrimination
Awareness and understanding of the origins and depth of HIV/AIDS stigma and discrimination can help communities address it effectively. Reinforcing confidentiality of care by providing testing, monitoring, and treatment services in integrated care settings, as opposed to freestanding test sites or HIV/AIDS care specific sites, could also help reduce stigma.

Denial or Fatalism
In populations of drug users, sex workers, and men who have sex with men (MSM), grantees observed that some clients are "in a state of denial" or have just given up trying to protect themselves. This requires innovative responses that are aimed at reaching consumers while providing them with real options.

Women's Health
Women are at particular risk of HIV infection because socially and culturally defined and reinforced gender roles commonly allocate less control and power to them in male-female interaction and relationships, as does economic dependency. The development of materials and strategies that address women's real experiences and utilize alternative and culturally competent views of women could improve access for these populations. Providing HIV services, particularly education and testing, through other social service providers, especially for those affected by IPV, could more effectively reach women who might otherwise have no contact with HIV-specific service providers.

Other Target Populations
Policies and programs must be tailored to the particular needs of specific populations at risk within hard-to-serve populations. The homeless population and older adults are two populations requiring attention that grantees highlight.

Religious Institutions
Collaborating with religious institutions to help them provide accurate information and community support to address HIV/AIDS could help reduce stigma and build community trust. Religious institutions often are well-positioned to access particular segments of hard-to-reach populations.

Community Mobilization
The most effective initiatives typically have roots and ownership in the community itself. Organizations viewed as outsiders, or whose staff do not reflect the diversity of the communities they are serving, will face challenges in communities distrustful of outsiders.

International Perspectives and Immigrant Populations
The growing body of international research and documentation reporting on effectiveness of HIV/AIDS policy and programs in other nations can inform efforts to combat HIV/AIDS in the United States. This may be particularly true regarding efforts addressing immigrant, migrant, and refugee populations in the United States.

The findings in this report are not exhaustive or definitive. However, they do provide evidence that with proper support, local organizations can increase their effectiveness in assessing local challenges in the HIV/AIDS epidemic. Further assessment projects, such as RARE, will continue to enrich findings and refine policy implications. Ideally, researchers will be able to use these findings to develop more standardized strategies. However, while HIV/AIDS is a global epidemic that requires a global response, the provision of HIV/AIDS services, like most of health care, will remain a local affair.

The following provides a quick reference summary of grantee findings, and particular successes and challenges.

Summary of Grantee Findings

Prevention and Treatment Services
- Prevention and treatment services are scarce.
- Transportation to services is poor.
- Information about services is scarce.
- Coordination among service providers is poor.
- Services are not available at major sites of risk behavior.
- Services should be available at well-known and non-threatening local sites.
- Many people do not trust medical service providers or public institutions.

- The stigma attached to being HIV positive prevents many people from seeking testing and treatment.

Education and Outreach
- Dangerous misconceptions and ignorance about HIV/AIDS persist.
- HIV/AIDS is often seen as a problem for "others."
- Educational and outreach resources are scarce, especially culturally and locally appropriate resources.
- Education should be nonhierarchical and nonstigmatizing, e.g., make use of peer group discussion, include affected people, do not rely on fear, and include comprehensive life skills and health education.
- Despite the spread of new communications technologies, in some communities word-of-mouth remains a very important way of spreading information.
- People often persist in behavior they know to be risky, or they refuse to acknowledge their risk.

Cultural Appropriateness
- Both education and services should meet the following criteria:
  - Provided in appropriate languages;
  - Designed for different levels of literacy (in any language);
  - Tailored to the local variety of beliefs pertaining to HIV/AIDS and health, in general;
  - Tailored to address local cultural norms regarding discussions of sex and sexuality;
  - Designed to address the particular local dynamics of HIV/AIDS, including the dynamics of the drug trade, drug use, sex work, noncommercial sexual transactions, and gender and intimate partner relations; and
  - Designed to work with and through locally trusted networks and institutions, such as churches, schools, and even bars and clubs.

Drugs, Sex, and Economic Opportunity
- Drug use and its expense foster behavior people know places them at risk, such as sex work, needle sharing, and sexual risk-taking while intoxicated.
- Lack of economic opportunity fosters circumstances that encourage the spread of HIV, such as drug abuse, reliance on sex work and sexual barter, low self-esteem, hopelessness, and fatalism.
- Both male and female sex work is common in a majority of the study areas.
- Numbers of both men and women trade sex for drugs, shelter, or other requirements as needs arise, but they do not always see themselves as prostitutes.

Sexual Identity
- Many men who have sex with men do not identify as gay.
- Cultural understandings of sexual identity, or of what constitutes sex itself, differ.

Gender, Power, and Intimate Partner Communication
- Patriarchy, economic dependence, and cultural taboos on discussion of sexuality greatly restrict women's chances to protect themselves in comparison with men.
- Fear of intimate partner violence can prevent both men and women from successfully negotiating safer sexual encounters.
- Cultural norms in some populations severely restrict discussion of sex and HIV, even between intimate partners.

Community Involvement
- There are often strong local preferences for greater community involvement and leadership in both planning and executing HIV/AIDS education and prevention efforts.
- Many common circumstances can complicate community-based action:
  - Great local cultural diversity;
  - The hidden nature of important populations, such as men who have sex with men;
  - Lack of cohesion within important populations;
  - Lack of cooperation among relevant local organizations; and
  - The need for special attention to confidentiality in a service strategy with a strong local or community base.
- While churches and other religious institutions can play important roles in HIV/AIDS education and prevention, they sometimes increase the stigma attached to HIV/AIDS by branding it the result of sinful behavior.

Risk and Social Networks
- Networks of sexual transactions and drug trade frequently stretch far beyond a given neighborhood to other parts of a city; to the suburbs; and even, in some cases, across State lines.
- Sexual networks link people who regularly engage in high-risk behaviors with people who do so only rarely.
- The increasing use of mobile phones and the Internet for making sexual contacts expands and complicates sexual networks.

Monitoring and Evaluation
- Careful monitoring of outreach and testing activities is vital to ensuring that services reach the intended populations.

Summary of Grantee Successes and Challenges

Grantee Successes
- Producing numerous findings useful in planning
- Providing important information to many sectors of participating communities
- Providing a basis for developing educational materials appropriate for participating communities
- Fostering interest in continuing to use the RARE methods as part of local planning processes
- Stimulating growth of new informal coalitions or linkages among stakeholders
- Nurturing the potential for collaborating more effectively in action against HIV/AIDS

Grantee Challenges
- Engaging certain policymakers, public health agencies, or representatives of religious institutions as project partners for lack of time, interest, or understanding
- Scheduling collaborative work involving multiple, diverse partners
- Securing full cooperation among service providers
- Identifying cultural experts
- Recruiting cultural experts as project partners for lack of rapport
- Reluctance of care providers, community leaders, or public officials to contribute data for lack of time, interest, or understanding
- Suspicion or hostility toward Field Team members
- Balancing the value of including diverse segments of the community in all phases of the RARE process with the value of quickly obtaining quality data
- Ensuring the street safety of the Field Team members
- Inclement weather

II. Introduction

History of the Rapid Assessment, Response, and Evaluation (RARE) Program
Across communities in the United States, the HIV/AIDS epidemic continues to affect minority and underserved populations disproportionately, particularly in urban and metropolitan areas where populations are racially and ethnically diverse. Attempts to improve prevention, testing, treatment, and care must include members of affected communities to be successful in addressing the epidemic. Active involvement of populations ensures that planning and implementation are anchored in data that are locally relevant and can capture emerging patterns of transmission and risk behaviors.

The Rapid Assessment, Response, and Evaluation (RARE) Program, under the Office of Minority Health (OMH), provides funding for implementation of the assessment portion of the RARE method in local projects. This method is intended to provide a process by which community members and stakeholders, elected public officials, public health administrators, and community-based organization representatives serving affected communities can collaborate to enhance education and prevention efforts, improve availability of testing, and develop appropriate care and treatment strategies through rapid assessment of populations most at risk. Local RARE project results can inform the response to the changing epidemic locally, ensuring that planning and implementation, as well as monitoring and evaluation, are based on the social and cultural context of the population served.

In 1999, as part of a comprehensive new DHHS initiative to address racial and ethnic disparities in HIV/AIDS, in collaboration with the Congressional Black Caucus and other members of Congress, the Crisis Response Team initiative began fielding technical assistance teams to assist public health officials in rapid assessment of local communities most affected by the epidemic. This assessment process, implementing the RARE methods with local planners and stakeholders, was first funded by the Office of Public Health and Science (OPHS) and implemented through the Office of HIV/AIDS Policy (OHAP). Since 2003, the RARE Program has been administered by OMH, most recently in partnership with the Office of Women's Health (OWH). Under the RARE Program, DHHS funding was provided to conduct the rapid assessment step in implementing the RARE process for HIV/AIDS planning locally.

To date, the RARE Program has been implemented in 63 locations, with each site having particular focus on local populations at risk for HIV/AIDS. Many of these communities have been in urban areas, including both Eligible Metropolitan Areas (EMAs) and Emerging Communities (ECs) as defined by the Ryan White CARE Act. These communities were identified as being disproportionately affected by the epidemic, focusing particularly on racial and

ethnic minorities and women, and, most recently, women affected by Intimate Partner Violence (IPV).

The RARE Program Grantees

The OMH RARE Program has funded two cohorts of grantees. Cohort 1 grantees were local public health departments in three phases, and selected community-based organizations (CBOs) in a fourth phase. Table 1 provides a complete list of Cohort 1 sites by phase and location.

Table 1: Cohort I Sites by Phase and Location

Phase I	Phase II	Phase III	CBO Phase
Atlanta, GA	Birmingham, AL	Atlantic City, NJ	Asian American and Pacific Islander Health Wellness Center (AAPIHWC), San Francisco, CA
Baltimore, MD	Columbia, SC	Baton Rouge, LA	
Chicago, IL	Corpus Christi, TX	Bradenton, FL	
Detroit, MI	Dallas, TX	Buffalo, NY	
Miami, FL	Houston, TX	Charleston, SC	
New Haven, CT	Jacksonville, FL	Charlotte, NC	Asian and Pacific Islander Coalition on HIV/AIDS (APICHA), New York, NY
Newark, NJ	McAllen, TX	Cincinnati, OH	
Oakland, CA	Memphis, TN	Cleveland, OH	
Philadelphia, PA	New York, NY	Ft. Lauderdale, FL	
Portland, OR	Phoenix, AZ	Hartford, CT	
U.S. Virgin Islands	Richmond, VA	Los Angeles, CA	Papa Ola Lokahi, Honolulu, HI
Washington, DC	San Antonio, TX	New Orleans, LA	
West Palm Beach, FL	San Juan, PR	Orlando, FL	Western Oklahoma Native American AIDS Task Force, Oklahoma City, OK (through the National Native American AIDS Prevention Center [NNAAPC])
	St. Louis, MO	Patterson, NJ	
		Rochester, NY	
		San Diego, CA	
		San Jose, CA	
		Seattle, WA	
		Trenton, NJ	
		Tucson, AZ	

Cohort 2 included CBOs that focused on underserved populations, with particular focus on one of two Priority Areas for OMH and OWH.

- Priority Area 1: Minority Women
- Priority Area 2: HIV/AIDS and Intimate Partner Violence in Women

Nine organizations were funded under Priority Area 1, and two organizations were funded under Priority Area 2. Table 2 provides a complete list of Cohort 2 sites by Priority Area and location.

Table 2: Cohort 2 Sites by Priority Area and Location

Priority Area 1	Priority Area 2
▫ AIDS Coalition of Volusia/Flager, Inc., Deland, FL ▫ Foothill AIDS Project, San Bernadino, CA ▫ Howard University Center for Infectious Disease Management and Research, Washington, DC ▫ International AIDS Empowerment, El Paso, TX ▫ Latino Family Services, Detroit, MI ▫ Prevention Effectiveness Consortium on Health and Education, Stone Mountain, GA ▫ Public Health Trust/South Florida AIDS Network, Miami, FL ▫ The ACCESS Network, Inc., Ridgeland, SC ▫ Youth Outreach Adolescent Community Awareness Program, Philadelphia, PA	▫ Community Education Group, Washington, DC ▫ Immigrant and Refugee Community Organization, Portland, OR

Each cohort contained a mix of grantees addressing a variety of local populations affected by the epidemic. These populations included urban and rural communities defined by intersecting categories, including, but not limited to, minority and ethnic communities; MSM; women; individuals affected by IPV; IV drug and other illicit drug and alcohol users; those with limited access to health and social services due to economic, insurance, or geographic limitations; and those for whom linguistic or cultural barriers influenced their access to services and care. Each grantee implemented the RARE assessment method as a first step in planning services for or improvements in existing services to the local service population. The results of their local RARE project were to inform the ongoing planning and implementation of services to the identified population.

The RARE Process
The RARE process, from which the RARE Program was developed, is a planning and implementation process based in social science methods for conducting population assessments, using mixed methods that are intended to produce reliable and verifiable quantitative and qualitative data. The process includes three steps for improving HIV/AIDS education and prevention, testing and counseling, and treatment and care efforts shaped for specific at-risk populations. Those steps are rapid assessment, rapid response, and rapid evaluation.

The rapid assessment step provides the mechanism for the local RARE project to understand the dynamics of the HIV/AIDS epidemic in the affected community. The rapid response step provides an opportunity for the RARE project team to implement innovative and population-specific public health programs and policy, thereby matching programs to the community served. The rapid evaluation step assists the RARE project team to monitor and evaluate

the newly implemented programs and policies in the affected communities, in turn, providing early valuable insight into implementation challenges, as well as lessons learned that can guide midcourse corrections.

The Local RARE Assessment Method

DHHS funding was provided to local public health departments and community-based organizations to conduct the assessment phase as a first step in the local HIV/AIDS planning process. The preliminary step in this phase was to identify and recruit members to constitute a Community Working Group (CWG). This group included community members, elected officials, public health administrators, community service organization representatives, and other stakeholders. The CWG convened with the RARE technical assistance team to identify and select the demographic and geographic area where the RARE assessment method would be implemented. The selection of this location, usually a targeted neighborhood, a census tract, or a zip code, was conducted through a thorough review of local surveillance, epidemiological, and public health data; and by gathering local knowledge and insights from CWG members to create a nexus of information regarding where the most affected community is located and what population should be targeted for the local RARE project assessment.

A technical assistance team from the RARE Program conducted a training orientation on the RARE process with the local CWGs. A RARE Field Team was created and trained in the RARE methods. Data collection in each designated RARE site involved tailored qualitative and quantitative field methods, including 1) mapping; 2) street intercept surveys; 3) focus groups; 4) cultural expert interviews (interviews with members of the study population) and interviews with other key informants (service providers, community activists, and stakeholders); and 5) direct observation.

The data collected included findings regarding the affected community, knowledge, beliefs, and behaviors associated with risk for HIV/AIDS, and barriers to accessing HIV/AIDS services for the specific population(s) in that community. The findings from the assessment were analyzed and a final project report was produced. This report detailed findings of the RARE assessment, what methods were implemented in the RARE process, and included recommendations for planning and continued implementation of the RARE methodology. These local RARE Project Reports were submitted to the grantee's DHHS funding agency. Additional details on the RARE methods are provided in the Findings chapter of this report (Section A. Grantee Assessment Methods).

The Purpose and Structure of this Report

LTG was contracted by Educational Services, Inc. (ESI), working in partnership with OMH, to conduct a review and systematic analysis of the local RARE

project findings in support of an evaluation of the RARE Program through the 2006 project cycle.

This evaluation report summarizes LTG's findings regarding the implementation of RARE. Following a description of the methods LTG used in analyzing project reports and other RARE materials, the findings are summarized, as follows: by grantee assessment methods used; by grantees' findings regarding the community studied, across grantees; by challenges identified in implementing the RARE assessment; by recommendations from the grantees for improved HIV/AIDS service delivery; by proposed planning methods as next steps in the RARE process; by training and staffing; and by grantee next steps in using the RARE process, as well as continued use of the RARE assessment methods. This report will then provide a discussion of major challenges and facilitators to the RARE assessment process, as well as major lessons learned and recommendations from the grantees in the implementation of the RARE assessment process. The report will conclude with a discussion of major challenges and lessons learned for the RARE program as a whole, as well as a discussion of the role that the RARE process can play in targeted local planning and implementation efforts to address the needs of the changing face of the epidemic.

III. Methods

This section details the methods used by LTG Associates in conducting the analysis of materials for the RARE Program evaluation. The evaluation centered on the review and analysis of materials available from RARE local project grantees. Materials were available for most Cohort 1 grantees (see Table 2, below). Cohort 2 grantees were still active at the start of the LTG RARE evaluation project, and LTG produced reporting guidance for those grantees to ensure that all necessary data would be captured in their final reports. A complete set of Cohort 2 materials was produced and made available to the LTG team as grantees completed their local projects.

LTG initially received a set of documents from ESI for review. This set included documentation about RARE's history and development, as well as reporting documents from implemented local projects. All documentation initially received pertained to the RARE Program Cohort 1. The types of local RARE project documents included project abstracts; final project reports; and preliminary and final evaluation reports, as well as final report PowerPoint presentations. A complete set of materials was not available for each grantee, but as indicated in Table 2, materials were available for most grantees.

Table 3: Materials Available by Grantee

Grantee - Cohort 1	Yes	No	Grantee - Cohort 1	Yes	No
AAPIHWC, San Francisco, CA	X		New Haven, CT	X	
APICHA, New York City, NY	X		New Orleans, LA	X	
Atlanta, GA	X		New York, NY		X
Atlantic City, NJ	X		Newark, NJ	X	
Baltimore, MD	X		NNAAPC		X
Baton Rouge, LA	X		Oakland, CA	X	
Birmingham, AL		X	Orlando, FL	X	
Bradenton, FL	X		Papa Ola Lokahi, Honolulu, HI*		
Buffalo, NY	X		Patterson, NJ	X	
Charleston, SC	X		Philadelphia, PA	X	
Charlotte, NC	X		Phoenix, AZ	X	
Chicago, IL	X		Portland, OR	X	
Cincinnati, OH	X		Richmond, VA		X
Cleveland, OH	X		Rochester, NY	X	
Columbia, SC	X		San Antonio, TX		X
Corpus Christi, TX		X	San Diego, CA	X	
Dallas, TX	X		San Jose, CA	X	
Detroit, MI	X		San Juan, PR	X	
Ft. Lauderdale, FL	X		Seattle, WA	X	
Hartford, CT	X		St. Louis, MO	X	
Houston, TX	X		Trenton, NJ*		
Jacksonville, FL	X		Tucson, AZ	X	
Los Angeles, CA*			US Virgin Islands	X	
McAllen, TX	X		Washington, DC*		
Memphis, TN	X		West Palm Beach, FL	X	
Miami, FL	X		Western Oklahoma Native American AIDS Task Force Oklahoma City, OK	X	

* Reports prepared by these grantees were not available for this analysis.

Grantee - Cohort 2	Yes	No
Washington, DC (Howard University)	X	
San Bernadino, CA	X	
Ridgeland ,SC,	X	
Miami, FL	X	
Philadelphia, PA	X	
El Paso, TX	X	
Detroit, MI	X	
Deland, FL	X	
Stone Mountain, GA	X	
Washington, DC (CEG)	X	
Portland, OR	X	

LTG created a document inventory in Microsoft Excel to account for the materials received from ESI. This inventory matrix was designed to track materials for review by location, cohort, and phase, through each step in review and analysis. LTG used this inventory to report back to ESI on the materials received in order to ensure completeness of the documentation available for the evaluation of the RARE Program.

LTG utilizes a team approach for this type of cross-site evaluation. A team of senior-level social science evaluation experts work under a Project Director, who also functions as an active member of the analysis team. Each member of the team is an active participant in designing and implementing the analysis approach to ensure that multiple perspectives are brought to bear on the work. In addition, as the analysis proceeds, adjustments are made to the approach to ensure that the questions asked match the data available, or to consider proxy data types where data are not available. Included in this work were the following steps.

- Conduct preliminary review of RARE program materials.
- Conduct preliminary review of a sample of Cohort 1 site reports to inform guidance for Cohort 2.
- Produce Final Report Guidance for Cohort 2.
- Develop an analysis template for review, analysis, and data management of all grantee materials.
- Conduct analysis of individual Cohort 1 and Cohort 2 grantee materials.
- Code analysis of individual grantee materials for cross-site analysis and synthesis.
- Conduct cross-site analysis and synthesis.
- Produce draft program evaluation report.

The LTG team conducted a rapid review of a sample of site reports to gain a preliminary understanding of the program and the types of data that had been submitted by grantees. The initial results of the review process were discussed among the members of the LTG evaluation team to consider common themes and identify areas for improvement of the Final Report Guidance for the Cohort

2 grantees. Special consideration was given to the fact that the new reporting guidance was for grantees composed mainly of community-based organizations, which may have less experience than Cohort 1 grantees, mostly Public Health Departments, in formal reporting of activities.

The Cohort 2 Final Report Guidance was informed by a review of Cohort 1 final reports to ensure comparability of data across the cohorts. Based on the available data from Cohort 1, and in anticipation of enhanced data availability from Cohort 2, the reporting guidance was developed to generate more robust and descriptive reports from Cohort 2. The guidance assisted grantees to report on common evaluation data categories across projects by answering a series of focused questions regarding the following themes: organizational data, local assessment methods, findings, challenges, recommendations, local planning steps, training and staff, and lessons learned. The Cohort 2 Final Report Guidance is included as Appendix A to this report.

The LTG team produced an analysis template for the review of all grantee materials. A single template was used to guide and focus the analysis on evaluation themes while allowing for unanticipated data to be captured, as well. These included data elements for both Cohort 1 and Cohort 2. As each set of grantee materials was reviewed, the analyst assigned synthesized the data into the analysis template electronically. Each completed analysis was a separate document that summarized data in grantee materials into standardized categories for an additional step of analysis and synthesis across grantees.

The initial analysis step was conducted on Cohort 1 grantee materials first, then proceeded to Cohort 2 materials upon receipt. These documents were stored on a password protected server accessible only to the LTG evaluation team. The entire process was tracked through spreadsheets that accounted for each step in the analysis process to ensure completeness. The LTG Project Director regularly cross-checked analyses against original materials to ensure completeness and comparability of data across grantees.

Once an analysis document was produced for each grantee, these documents were coded and sorted using Atlas.ti, a computer-assisted, qualitative data-analysis tool. Atlas.ti is a data management tool that allows the researcher to digitally sift through hundreds of pages of text, identifying discrete issues and coding text passages with a standardized code list developed from the data. The code list was based on the common themes, described above, that structured the Cohort 2 Final Report Guidance, based on available data from Cohort 1 and evaluation reporting standards.

Using the codes, these themes were electronically linked to sections of text in each grantee analysis template document, which allowed for conducting searches across the documents for patterns and trends across all grantees. It

also allowed for sorting among particular sets of grantees to see whether significant differences, such as across the cohorts, were reported. Sorting in this manner allowed the analysts to probe deeply within each theme to look for common findings to synthesize, while retaining a complete data set for each theme to ensure that unanticipated data are also captured and reviewed.

Throughout this process, emerging themes and broader implications were discussed in regular team meetings. The result of this work is the current evaluation report in which data are presented at three levels of synthesis. In the following chapter, the grantees' findings are presented. First, a brief overview of the local RARE process and data collection methods is provided, followed by a synthesis of grantees' findings from the conduct of the RARE assessment. This includes sections on recommendations, challenges, ongoing or subsequent planning steps proposed, training and staffing issues, and discussion of adoption of RARE in the local communities and enhancements of networks. In the following chapter, major lessons learned that appear in the synthesis of grantees' findings are presented, including recommendations to others who may be implementing a RARE assessment. Finally, in the concluding chapter a summary of implications of the RARE Program data for HIV/AIDS planning and service provision is presented.

IV. Evaluation Findings

The RARE Program evaluation findings are presented in this chapter. The local RARE grantees focused on a variety of populations identified as being significantly at risk for HIV infection and for whom significant barriers to care were evident. Of particular interest were emerging populations about whom little data were available on patterns of risk behavior and access to services.

Despite the considerable differences in the populations and settings, all of the grantees went through a series of program stages as they investigated their respective populations and identified their risk parameters. It is important to briefly review these stages to contextualize the findings below. Initially, grantees identified organizations, groups, and individuals who could provide resources and accurate information about high-risk behaviors. These included activist organizations, local health departments, service providers, and other community stakeholders. This stage also identified potentially influential groups that had either presented barriers to service provision or had not yet taken an active role in facilitating service provision.

Grantees then gathered data to describe risk behaviors, who engaged in them, and where and when they did so. Cultural experts provided descriptions of different risk behaviors associated with the transmission of HIV, using familiar categories to describe the persons, activities, times, and places. For example, a public park after dark was a "hot spot" for anonymous sex and drug activity for MSMs and sex workers. These descriptions relied on individual experts' experiences. Such data, along with available epidemiological data, provided the grantees with a sense of the patterns of risk behavior. Descriptions of the local manifestations of risk behavior are a central feature of the overall findings presented in this section.

Grantees identified factors that facilitated and perpetuated risk behaviors. Grantees typically described these factors as barriers to care, rather than as factors that drive or facilitate particular high risk activities. Some of the factors were psychosocial while others were more structural in character. Lack of awareness of risk or services perpetuated behavior. The stigma associated with an HIV positive status often discouraged people from seeking care. The denial of risk, or its converse, fatalistic acceptance, discouraged people from taking steps to reduce risk. Intimate Partner Violence and unequal gender relations created challenges for women who sought to reduce risk. Structurally, grantees noted that the lack of services, fears of loss of privacy, the mistrust of health departments and other organizations, and lack of organizational resources, allowed high risk behavior to continue or spread unabated. Finally, broader socioeconomic factors such as unemployment, poor educational systems, and declining neighborhoods decreased peoples' opportunities to make legitimate livings and access quality health services.

This chapter summarizes and synthesizes data across the local RARE projects as reported in available materials from the grantees. The section on grantee assessment methods reviews the recruitment of collaborators and CWG members, as well as the types of issues addressed and geographic areas targeted. This section also provides an overview of the populations studied and the types of data gathering methods used. Training and staffing issues are then discussed. The grantees' findings section reports on the central themes that emerged from the local RARE process related to HIV transmission and the provision of HIV/AIDS related services, including unanticipated findings. Recommendations proposed by grantees to address the issues identified in their findings are summarized, and a section on grantee planning methods describes the planning steps proposed by grantees after completion of the assessment process to produce action steps based on the data generated. Challenges encountered in recruitment and data collection methods are then summarized. A section on the adoption of the RARE method at the local level is provided, and training and staffing issues are discussed.

IV.A. Grantee Assessment Methods

What kinds of people and organizations were involved in the RARE Process?
A variety of people from each grantee site participated as collaborators or Community Working Group (CWG) members in planning and implementing the RARE assessment method in the community selected. The following types of people and organizations were included.

- Elected public officials
- Public health department representatives
- Medical providers
- Faith-based and community-based organizations, such as local churches and AIDS activist organizations
- AIDS service organizations
- Ryan White CARE Act Consortia members
- Private business representatives
- Housing officials
- Representatives from local and State educational institutions
- Police departments
- Ethnic organizations addressing HIV/AIDS issues in their communities

In addition, grantees worked with organizations that addressed special needs of the population, such as a local Domestic Violence Task Force, when assessing HIV/AIDS issues in populations affected by Intimate Partner Violence (IPV).

How were participants recruited?

Many grantees did not specifically report how RARE collaborators or CWG members were identified or recruited. However, those organizations that did report on this process stated that many of the participants were identified through local networks, as well as by existing advisory boards in the communities of interest. Largely, grantees invited community leaders, community members, and service providers with strong ties to the community to serve as experts on the population studied. Often, working through networks, they would identify individuals who filled specific roles or could answer specific questions in the study to participate either as formal members of the CWG or through direct data gathering activities, particularly when looking at populations with special needs.

What principal issues were addressed?

The grantees focused their efforts on understanding the barriers that people at risk for HIV faced when accessing and utilizing services, including education, testing, counseling, and care. Most grantees addressed the intersections of risk for HIV and other factors, such as cultural background, specific sexual practices, and other risk behaviors, such as drug use and commercial sex work.

The grantees recognized that understanding risk is of particular importance to education and prevention efforts, especially when working with emerging populations. While risk is largely defined in terms of behaviors, such as specific sexual practices, the grantees addressed other parameters that intersect with sexual behavior to increase risk in certain populations. Unprotected sex and IV drug use can directly affect the spread of HIV within a population. Such activities may be clustered in particular populations, as among sex workers and those who trade sex for illicit substances. In addition, the grantees addressed population characteristics that may themselves serve as barriers to message dissemination. Messages designed for gay populations may not reach MSM who do not gay identify. In addition, certain special populations may be particularly difficult to reach, such as individuals affected by IPV who may be unable to negotiate protected sex with their partners.

When looking at direct services, such as testing, counseling, and care, issues of access, in terms of availability and affordability, as well as barriers to access, were addressed by grantees. Grantees addressed structural issues, such as the presence of services locally or the ability of the population studied to pay for services. In addition, they looked at barriers to access, including lack of service availability in the primary language of those served, cultural beliefs about health and medicine that complicate mainstream medical approaches to sexual health, the effect of stigma and shame on choices individuals make, and lack of trust that government and other institutions will protect the individuals' confidentiality.

What kinds of geographic areas?

The majority of the sites chosen for the RARE assessment project were local communities in urban centers where the risk for HIV infection was deemed to be greatest. Many areas included transient housing or mixed housing neighborhoods where economic opportunities were limited. Such sites intersected with other risk behaviors and illegal activities, such as commercial sex work, the selling of drugs, and drug use and abuse. In many cases, risk associated with HIV was seen as related to factors endemic to the geographic area, such as low socioeconomic status (SES), minority communities where HIV rates are disproportionately high. In others, however, a newly emerging population was identified as at increased risk of HIV entering the community through interaction between residents and seasonal workers or commercial sex workers. In still others, the population studied was itself transient in the geographical area, as with MSM looking for anonymous sex in public spaces such as parks.

How were the populations defined?

Grantees defined their study population through a variety of characteristics that identified local patterns of the epidemic. These included demographic characteristics, such as race or ethnicity, gender, sexual preference, age, and geography. Most grantees focused on resident African-American, Hispanic, Native-American, or Asian-American/Pacific Islander populations. Others focused on newly arrived immigrant or refugee populations from South Asia, other Asian and Pacific Islander countries, Haiti, the West Indies, Somalia, and other African countries. Males and females were studied within both the heterosexual and the homosexual communities. Of particular interest were MSM (including those who do not gay self-identify), and high-risk heterosexuals (HRH) who participate in the sex trade, and women of childbearing age. The populations ranged in age from 18 to more than 50.

In addition, the grantees categorized their populations using cultural and linguistic parameters and socioeconomic status. Grantees also focused on behavioral characteristics of populations, such as likelihood to engage in unprotected sex and drug use, which significantly increase the potential for HIV transmission within the populations defined otherwise. Many grantees focused on specific populations, such as sex workers or their clients, MSM, those engaged in anonymous sex, and those who trade sex for drugs. Many grantees, particularly in Cohort 2, focused on populations with special needs, such as women in IPV relationships who are unable to negotiate safe sex practices with their sex partners.

What data gathering methods were used?

All grantees report using each of the recommended research methods: direct observation, mapping, street intercept surveys, focus groups, and interviews with key informants. The types of people from whom data were gathered varied, of course, with the focus of the investigation, but all sites endeavored

to gather data from both members of the at-risk populations of focus and significant figures in the larger community:

- HIV and other health and social service providers;
- community leaders of various kinds, usually including religious leaders;
- local business people; and
- local government officials.

Many reports do not indicate exactly how participants in focus groups or interview studies were recruited. Those that discuss this often say that they identified and recruited participants through contacts with community-based or government organizations and, in a number of cases, used a "snowball" technique, e.g., they recruited a small number of initial participants and identified and recruited additional participants on the basis of the initial participants' recommendations and contacts.

Grantees used direct observation, from short time-course periods to multiple 24-hour observations and mapping, largely to gather and organize data on research sites already chosen, but also to help select research sites. A common purpose of direct observation and mapping was identifying locations of risk activity (such as drug and sex trade), HIV and other health and social services, and centers of community socializing and information exchange.

Street intercept surveys often targeted particular segments of the population, but also were used to sample widely. While a few grantees conducted as few as 25-50 street intercept interviews, numbers from 100 to 200 were more common. All grantees conducted at least a few focus groups, usually forming distinct groups from among segments of the population such as the following:

- Members of particular sub-populations of interest, such as Hispanic women or South-Asian immigrants;
- Particular at-risk populations, such as sex workers or drug users;
- Community activists;
- Elected officials;
- HIV service providers; or
- Community members directly affected by HIV.

Interviews were used to gather data from individual members of similar key groups. Numbers of interviews conducted ranged from about 30 to about 90. Some grantees used focus groups not only to collect initial data but also to review data collected using other methods and discuss potential responses to the issues identified.

An important aspect of the RARE assessment process is the use of multiple methods to gather data from a variety of persons with local knowledge of the

epidemic. This allows for various expert perspectives to be engaged and incorporated into the assessment results. Moreover, it allows for triangulation of data to test validity. Many grantees reported specifically that multiple perspectives yielded triangulated data rapidly, and many reported that they used one method, such as focus groups, to specifically validate or expand upon data gathered through another method, such as observations or street intercept surveys. Altogether, from participant recruitment to specific data collection methods, the RARE process is designed to enhance the capture of locally validated relevant data for planning purposes.

IV.B. Training and Staffing

In preparation for local RARE projects, the RARE program emphasized the training and staffing of the local RARE teams to enhance the collaborative effort between public health agencies and other project partners. This training focused both on the overall RARE assessment process and on specific field methods to be used.

Each site designated a local Field Team Coordinator (FTC), an individual with knowledge and experience in the community and of HIV-related issues, who agreed to commit at least 320 hours for the length of the project. The FTC was in charge of coordinating the efforts of the CWG and collaborators, as well as for selecting and supervising the six to eight members of the Field Team who conducted the data collection. The FTC was also responsible for the analysis of data collected and reporting back to their funding agency. The Field Team Coordinator received a 2- to 3-day orientation in Washington, DC.

In addition, members of the Field Team, including the FTC, received a 4-day RARE methods training onsite. The local RARE Project timeframe was compressed to a 12-week period of performance. As a result, training was conducted as the Field Team was selected and scheduling completed to ensure that teams were in the field as early as possible. The training, provided by an HHS-consultant, was an opportunity to review the RARE methods and develop the necessary skills to implement them in the study population. The training included an introduction to the RARE methods, as well as practical advice in adapting the methods to the specific population studied and to local conditions.

The training focused on field methods, including mapping, direct observation, interviewing, and conducting focus groups. The training was conducted through simulations and role playing, and included discussion of topics such as "street smarts," protecting confidentiality, informed consent, recording, and security issues. Trained team members were expected to be available for a total of 166-240 hours, approximately 15-20 hours a week with a certain degree of flexibility depending on the sequencing and scheduling of the fieldwork.

Grantees from Cohort 1 did not explicitly report specific participation in RARE orientation and training other than a brief mention of the name and background of the FTC and the number of people participating as members of the Field Team. However, it was implicit in the reporting that both FTCs and Field Team members attended the training sessions provided by OMH.

Cohort 2 grantees did report on specifics of training in response to direct questions posed in the guidance. These grantees noted that Field Team members were selected on the basis of their knowledge of or connections with the study population. In several cases, members of the study population served as Field Team members, enhancing the grantees' ability to reach into the community through direct relationships that fostered trust. This was reported to significantly enhance the validity of their findings. Grantees also reported that the training provided to the Field Team members prepared them for the field activities, but that analysis of the data captured was often challenging because of time constraints, particularly where indepth expert interview data required transcription and systematic analysis.

Very few grantees, in both Cohorts 1 and 2, reported members of the Field Team leaving the project before the end of the activities. In those cases, most sites reported no significant effect on the development of the RARE process because staff departure occurred early enough in the project to allow for replacement. A few grantees reported minor delays in Field Team activities because of the need to train replacement Field Team members. Generally, grantees reported that Field Team members were fully engaged in and excited about the RARE process, and although scheduling placed burdens on the Field Team members, they remained dedicated to seeing the process to completion.

IV.C. Grantees' Central Findings

1. Introduction

The RARE grantees worked with a wide variety of populations at risk for HIV, most often from injection drug use or unprotected sex. Unprotected sex was common not only in the context of men or women exchanging sex for drugs or money (either formally or informally), but also among men having sex with men, or people having unprotected sex within what at least one party assumes is a monogamous relationship. What grantees found was not individual risk behavior but often interlocking, shifting social networks connecting the worlds of drug trade and drug use with those of commercial sex, sexual barter, casual noncommercial sex, and comparatively stable sexual partnerships. Understanding such networks is vital to understanding risk even in places where people's networks substantially overlap, forming relatively tight-knit communities or neighborhoods. Some individuals, however, participate in

loosely constructed and reconstructed social networks focused on sexual activity, drug use, or combinations of both that cut across apparent social and geographic boundaries. Such networks touch even those who may be connected to them through only a single relationship, further complicating issues of HIV risk reduction.

Grantees used the RARE process to better understand the geographic, temporal, and social dynamics of high-risk behaviors. The findings in this section are grouped under several interconnected themes that reflect grantees' efforts to identify and define the populations at risk, and understand why they continue to be at risk for HIV and what can be done to reduce that risk.

All of the grantees worked in the context of common emerging issues regarding HIV/AIDS. Antiretroviral medicines have significantly improved the outcomes for people who contract HIV, and altered attitudes towards HIV, fostering both hope and, in some cases, unwarranted relaxation of caution. Demographic shifts in HIV transmission, in generational terms and in terms of ethnicity and gender, have been significant. These factors have required public health activists to identify emerging at-risk populations and develop new strategies for reaching them.

The data describe both research participants' own perceptions and their understanding of the perceptions of the people of the area in which they live, i.e., general "community" attitudes or perceptions. These two kinds of data are not always distinguished in reporting. For purposes of analysis we are assuming, as the researchers have, that as "community experts" or "cultural experts," those who describe the perceptions of others are reliable guides.

The research reports often speak of particular racial, ethnic, or cultural groups, but this analysis does not emphasize the association of perceptions, beliefs, or behaviors with particular groups. While the RARE process allowed investigators to explore some aspects of local manifestations of the HIV epidemic more deeply, it remains an exploratory form of research. Associating particular HIV-related beliefs or behaviors too closely with particular groups on the bases of such exploratory findings could be misleading. In addition, group definitions and boundaries are not self-evident, even to their members, and findings applicable to a particular local population may also be more widely applicable.

2. Summary of Findings

Adequacy of Prevention and Treatment Services

The reports indicate that the following circumstances are common regarding prevention and treatment services.

- Too few services are locally available.
- Transportation to services is inadequate.
- However adequate the quantity of services, people often do not know what services are available. Some reports state explicitly that Information about services is not adequately disseminated.
- Many service providers themselves are not aware of other providers and are unable to coordinate their efforts.
- Many service providers who are aware of one another fail to coordinate their efforts.
- Services often are not provided at the times and places where the most risk behavior occurs, such as known sites of public drug use or trade; prostitution; or casual, often anonymous, sex. The majority of reports identified sites, often referred to as "hot spots," in their study areas where people gathered at customary times to take part in all these interrelated risk behaviors—purchasing drugs to enhance sex, trading sex for drugs, or sharing both drugs and sex. "Hot spots" were found in many kinds of locales, including bathhouses, bars, clubs, public parks, parking lots, street corners, bus stations, and bookstores; and some sites reported discovering more such locales than anticipated. Some reports contend that providing services at such times and places would be more effective; others, however, contend that some populations may find such an approach intrusive and threatening.
- Schools often are well positioned, both geographically and culturally, as locations for services.
- Services could be made available more effectively through sites that are well-known and non-threatening local landmarks or gathering places in specific communities, such as a particular convenience store, barbershop, or vacant lot.
- Many people in minority and marginal populations do not trust medical service providers or institutions. Some also report that they find long waiting times humiliating and that they are not treated with respect.
- Many people do not want to go to service locations closely associated with HIV because they fear they will be stigmatized.
- In some areas, people appear to welcome mobile testing, counseling, and treatment units.

These findings provide insight into factors shaping the effectiveness of local service provision, but they also illustrate the difficulty of generalizing from one site to others, e.g., with regard to the effectiveness of providing services when and where risk behavior is most common. It also is clearly necessary to assess for any particular site the relative importance of what services are actually available, the adequacy of efforts to inform people about them, and the effects of lack of mutual knowledge and coordination among service providers.

HIV/AIDS Knowledge and Educational Efforts

The reports indicate that the following circumstances are common regarding HIV/AIDS knowledge and educational efforts.

- Dangerous misconceptions and ignorance about HIV/AIDS persist, even in areas where the majority of study participants exhibit sound basic knowledge. For example, the idea that HIV is a manmade virus is reported from several sites.
- Among the most common impediments to better understanding of HIV is a tendency to see it as a problem for "others," such as other races or ethnic groups, other age groups, or people with other sexual preferences.
- There are too few educational and outreach efforts.
- There is a lack of culturally appropriate educational efforts; educational materials or outreach are not available in the necessary languages or at appropriate levels of literacy, or are not informed by knowledge of cultural beliefs and attitudes regarding health, sex, or gender roles.
- The educational methods used are not always the most effective. Findings from some sites suggest that education is most effective when it is nonhierarchical and nonstigmatizing, makes use of peer group discussion, includes affected people, does not rely on fear, and includes comprehensive life skills and health education.
- It is reported that in some populations, cultural norms severely restrict discussion of sex and thereby, of HIV, even between intimate partners. This can greatly restrict direct educational efforts. One site, however, illustrated the danger of making assumptions about people's readiness to discuss sexual matters, reporting that attitudes in the community in question appeared to be changing, permitting many open and "spirited" discussions of HIV.
- Education and information often are not provided at the times and places at which there is the most risk behavior, such as known sites of public drug use or trade, prostitution, or anonymous sexual encounters. As noted above, however, it cannot be assumed that doing so will be more effective with any specific population.

Again, the reports provide valuable general insights while making clear the need to base educational tactics on indepth, site-specific knowledge. In addition, as discussed below, data from the reports emphasize that effectively purveying information is sometimes only the beginning of effective prevention.

Denial

Data from many reports indicate that people often persist in risk behavior even when they appear to possess reasonable basic knowledge of what constitutes

risk. The prevalence of what reports almost universally call "denial" helps explain this phenomenon.

Many sites report that it is common to find that people whose behavior might put them at risk refuse to acknowledge their risk. This leads many to avoid testing because it might force them to confront the reality of risk. The data suggest various roots of such denial. It is reported that many who deny the possibility of HIV infection do so simply because they find the prospect too frightening. Some think that their youth and strength protect them. As noted above, some believe that HIV is something that happens to "others." The data also suggest that at least some who live in denial find it psychologically difficult to recognize that they may be similar to "others" because these are the very people they routinely stigmatize. Men who have sex with men, but do not identify as gay, and women who engage in occasional sex for money or drugs, but do not consider themselves professional sex workers, may be especially prey to this kind of denial.

The Relation of Drugs to Risk Behavior

Study participants in many sites observe that one major reason for persisting in behavior people know places them at risk is drug use. They observe that for people who are addicted, knowledge of longer-term health risks carries very little weight. Use of IV drugs carries its own risk of infection if users share needles. The need for drugs also pushes both women and men to engage in unsafe sexual practices, either as regular sex workers or in occasional barter of sex for drugs. Study participants also observe that drug or alcohol intoxication, whether or not in the context of addiction, can impair people's judgment regarding sexual practices, undercutting the influence of their knowledge about health risks. A few study participants, however, challenge this idea, contending that for many, drugs and alcohol simply make it easier to do what they already intend to do.

Sex Work, Sexual Transactions, and Sex Play

The data help illuminate the variety of social and cultural contexts in which sexual activity can put people at risk for HIV infection in the study areas.

- Both male and female prostitution/sex work is common in a majority of the study areas.
- The financial burden of drug addiction, as well as general financial desperation in areas where economic opportunities are scarce, helps push people into sex work.
- Many sites also report that many people engage in occasional sexual transactions that are more like barter than professional sex work; i.e., numbers of both men and women trade sex for drugs, shelter, or other requirements, as needs arise.
- Some study areas also include specific sites, such as bars, clubs, vacant lots, or bus stations, where people in search of sexual partners gather. These are

sites where not only sex work, but also casual, non-commercial sex takes place or is arranged.

- People who trade sex for money, drugs, or other things do not always see themselves as engaged in prostitution. For example, research in one study site identified "a group of young women who exchange sex for money, drugs, or other support with groups of men living in . . . several apartment complexes," but do not self-identify as prostitutes and do not see theirs as risk behavior. The data do not tell us this, but given the common tendency to see "others," often among them prostitutes/sex workers, as at risk for HIV, it is possible that how these young women assess risk is related to how they understand their sexual behavior.
- It is important that sites of sex work, sex-for-drugs, and recreational sex are often known far outside particular neighborhoods and draw participants from other neighborhoods, city suburbs, and even other cities and States.

Such findings illustrate the complexity of the sexual nexus of HIV transmission. Findings regarding sexual identity and behavior add an additional dimension to this complexity.

Sexual Identity and Sexual Behavior
It is reported from many sites that many men who have sex with men, either exclusively or in addition to heterosexual sex, do not identify as gay. In some cases, this may be a form of the kind of denial described above. It may also reflect particular cultural understandings of sexual identity or of sex itself. One site reports that men of a particular ethnic group do not recognize oral or anal sex with other men as sex at all. Such findings emphasize that prevention information targeting "gay" men may reach some men who need it, and that some, perhaps women as well men, may not recognize that talk of "safe sex" applies to them.

Gender and Intimate Partner Relations
The social and cultural dimensions of relations between sexual partners play primary roles in the dynamics of HIV transmission and prevention. For the most part, social and cultural factors greatly restrict women's chances to protect themselves in comparison with men. The principal relevant findings are described below.

- Women in some sites perceive themselves as less likely to have more than one sex partner than men.
- In some populations investigated, it is culturally acceptable, even approved, for men to have multiple female sexual partners.
- Some sites report that transmission from their primary sexual partners is a major risk factor for HIV in women.
- It is reported that in some populations primary sexual partners are less likely to use condoms than people engaged in occasional sex. While the data do not provide explicit reasons for this, they suggest that in some cases one

partner may assume (sometimes incorrectly) the other partner is monogamous, or one or both partners believe they are aware of the other's health status.

- One site reports that many MSM assume that being in a relationship means they do not have to practice safe sex.
- In some populations women may find it difficult or impossible to convince a male partner to use a condom because the request may be read as evidence of the woman's infidelity, suspicion of the male's health or fidelity, or simply a challenge to male prerogative.
- Cultural prohibitions against open discussion of sex and sexuality impede open communication about matters important to HIV prevention between intimate partners in many populations.
- In some populations a tradition of patriarchy and, in some cases, fear of Intimate Partner Violence (IPV) make it difficult for women to discuss safe sexual practices with male partners, from condom use to male multiple partners, or to protect themselves from male partners' unsafe sexual practices. Women at risk of IPV may knowingly accept unsafe sexual practices because of the danger of refusing.
- Strong patriarchal traditions in some populations make it difficult for women to protect themselves against violence, including sexual violence, from their male partners.
- IPV is frequently underreported. In some populations women who are the victims of IPV may not report it because it is culturally defined as shameful to be the recipient of such violence.
- Some sites report that there are few resources available to women who have been the victims of IPV. It is also reported that many women have learned that they cannot count on the support of law enforcement agencies in cases of IPV.
- The economic dependence of many women on men, especially women with children, exacerbates cultural approval of male dominance.
- To the extent that low self-esteem fosters drug use, the subordination of women contributes to drug use and the attendant risks of HIV infection.

Understanding such issues is vital to designing effective prevention measures. In the sphere of gender and intimate partner relations one perhaps sees most clearly how wide the social and cultural field of prevention activity must be.

Stigma
The stigma attached to being HIV positive, or even the suspicion of being HIV positive, is cited over and over again as a reason why people do not seek testing and treatment. Being tested or using condoms, it is reported, can inspire suspicion that one has good reason to fear being infected or must in fact be infected. Seeking treatment, if it becomes known, confirms publicly that one is infected.

Many reports do not address the origin of stigma in HIV, but the data do suggest several reasons for stigmatization, of which the following are most prominent.

- A person assumed to be infected with HIV is assumed to be dangerous to others.
- Some see HIV as punishment for sinful behavior, and it is safe to assume that when people speak of sin in the context of HIV, many of them are talking about drug use and perceived sexual misconduct.
- Many people explicitly associate HIV with behaviors of which they disapprove, such as IV drug use, prostitution or frequenting prostitutes, homosexual sex, or infidelity.

It is interesting, however, that the data suggest HIV infection may be more strongly and widely stigmatized than the kinds of behavior that put people at risk of HIV infection, i.e., that there may be a stigma gap. Why such a gap might exist may be in part explained by data from various sites.

Studies from many sites indicate that their residents are unhappy about the amount of drug dealing, drug use, commercial sex, and more or less public, noncommercial sex going on in their neighborhoods. But many respondents do not speak disparagingly about those who engage in these behaviors or report that people in general strongly disapprove of the individuals who engage in them. In particular, the data reveal comparatively little stigmatizing of those engaged in sex work and drug use. It is clear that some residents of the study areas do not understand the links between such behavior and HIV infection. Also, some residents of some study areas value certain risk behaviors positively, e.g., men having multiple female sex partners.

A much more widespread phenomenon, however, that would help explain a stigma gap is empathy for those who engage in sex work and drug use. Many study participants understand or report that the community in general understands these behaviors less as moral failures than as responses to harsh circumstances: lack of other economic opportunities; lack of education; low self-esteem; "hopelessness"; and "emotional pain" associated with poverty, discrimination, or histories of sexual or other forms of physical or psychological trauma or abuse. Many sites reported a perceived relationship between abusive or traumatic experience and higher risk of HIV infection, with only one site explicitly noting the absence of such a local understanding.

It is significant that some sites also report that local religious institutions contribute to the stigma attached to HIV by branding it as the wages of sin. RARE findings from these and other sites emphasize that in many communities it will be difficult to reduce stigma without the support of religious leaders.

The Role of the Community

The data indicate that implementing the RARE process made at least some researchers aware of the importance of understanding the nature of HIV/AIDS in one's own community, not just in general, e.g., the importance of understanding local prevalence and the particular risk profile of the local population.

Data from a number of cities also indicate strong preferences for greater local community involvement and leadership in both planning and executing HIV/AIDS prevention and treatment efforts, and provide specific arguments for this position. The following are prominent among arguments reported for a more strongly community-based approach:

- The value of providing culturally and linguistically appropriate education and services; and
- Although one site reported that the local population regarded government agencies as potential sources of assistance, it was much more common to find widespread mistrust of external organizations and their emissaries, including government agencies. At least some of this mistrust appears to be based on disappointment in the outcomes of past programs and projects coming from outside.

The weight of opinion among study participants regarding the importance of providing culturally and linguistically appropriate education and services is especially great if we include not simply general calls for "appropriate" education and services, but also calls for providing education and services that meet these criteria:

- Offered in particular languages;
- Designed for different levels of literacy (in any language);
- Tailored to the local variety of beliefs pertaining to HIV/AIDS and health in general;
- Designed to address the particular local dynamics of HIV/AIDS, including the dynamics of the drug trade, drug use, sex work, non-commercial sexual transactions, and gender and intimate partner relations; and
- Designed to work with and through locally trusted networks and institutions, such as churches, schools, and even bars and clubs.

The data provide insights into distinctive local conditions important to HIV/AIDS prevention and treatment in a number of RARE sites, such as the different levels of understanding of HIV/AIDS of long-resident Hispanics and recent Hispanic immigrants in one neighborhood, impediments to open discussion of sex among South Asians in another neighborhood, and reportedly bitter rivalries among church leaders in still another. Data from some studies illustrate how important very detailed knowledge of the local scene can be to successful action against HIV/AIDS. In one site, for example, investigators learned that it was important not only to provide condoms at the right times

and places but also to provide particular brands of condoms (*Rough Rider* condoms were preferred to *Lifestyles*, although the basis for this preference was not reported).

The data also indicate circumstances common to many RARE sites that impede community-based action.

- A given geographical area may be the home of a multitude of cultural communities.
- Important populations in some areas may not only be hidden but may also not constitute cohesive groups, in particular, men who have sex with men.
- While networks of sexual transactions and drug trade are often central to HIV epidemiology, they frequently stretch far beyond a given neighborhood to other parts of a city; to the suburbs; and even, in some cases, across State lines.
- Participants in a number of studies report a lack of "community cohesion."
- Participants in a number of studies report that relevant local organizations and agencies do not collaborate and coordinate their efforts; in some cases, there is even rivalry among them.

Community-based approaches clearly require careful definition of the community of interest and detailed knowledge of its social and cultural circumstances.

Confidentiality

The potential benefits of deeper local understanding that might be realized through a service strategy with a strong local or community base also make special attention to confidentiality necessary.

- A number of study areas report that people are reluctant to make use of HIV-related services because they fear that their service use or the information provided to the service provider will not be kept confidential, exposing them to stigma and discrimination. Some participants even report people going to other parts of a city or to other cities to obtain services in order to avoid this risk.
- In addition to tightening standard procedures for ensuring the confidentiality of client information in service sites, some reports suggest that locating HIV-specific services in facilities that provide a variety of less sensitive health and social services can make it possible to use HIV services with less fear of public knowledge.

Confidentiality must be, of course, a prime consideration for providers of HIV education and services in any context.

The Role of Religious Institutions

The data indicate that churches and other religious institutions play important roles pertaining to HIV/AIDS, but that these roles are not always positive. Below are the principal findings related to this issue.

- Some churches already provide valuable services and leadership.
- In many areas, churches are well situated both geographically and culturally to provide HIV education and services.
- In a number of study areas, it is reported that at least some churches avoid addressing HIV issues because, like many individuals, they regard association with HIV as stigmatizing.
- Some sites report that belief in religious healing prevents some people from seeking conventional medical services. Churches or other religious institutions are in a position to discourage use of religious healing as a replacement for conventional medical care.
- It is reported that some churches go beyond avoiding association with HIV to preaching that HIV infection is punishment for sinful behavior, thereby exacerbating the problem of stigma. Some churches or church leaders who regard HIV as the wages of sin are reluctant to participate in HIV education and service initiatives. (Such a stance may also explain the low level of participation of churches in RARE activities in some sites.)
- It is reported that in many areas religious institutions do not have a history of the kind of collaboration that would make them a more effective force against HIV/AIDS.

These findings indicate that leadership from churches and other religious institutions is extremely important in many communities for discouraging rejection of conventional medicine, addressing stigma at the local level, and creating stronger local collaborative HIV initiatives.

Wider Economic and Social Conditions
Over and over, study sites report that joblessness, lack of economic opportunity, and lack of education are among the roots of circumstances that encourage the spread of HIV, such as the prevalence of drug abuse, sex work and sexual barter, low self-esteem, hopelessness, and fatalism.

3. Unexpected Findings

The reporting format asked RARE sites to identify any unexpected findings. Because of their importance to particular issues, some of these have been incorporated in descriptions of the findings above. In particular, sites reported that they did not expect to find "incredible rivalries and competition among local pastors and churches," church leaders reluctant to engage with HIV issues, and religious healers in a rural Southern community influencing decisions to seek HIV care.

Some findings reported as unexpected from individual sites were nevertheless quite common among all sites, e.g., high numbers of young people engaging in risk behavior, limited and poorly integrated medical and social services, and large numbers of Caucasian sex workers.

A number of findings reported below as unexpected, were, however, distinctive.

- Pharmaceutical companies are aggressively marketing new, more effective antiretroviral medications using messages that "[make] light of living with AIDS." The effects of this among MSM are poorly understood but may be significant.
- When considering sexual networks, it is important to take into account the increasing use of mobile phones and the Internet for making sexual contacts. Such technologies give "hot spots" a new and expanding dimension.
- Despite the spread of new communications technologies, in some communities word-of-mouth is an important way of spreading information. One report notes that in the small, rural community in question, information obtained this way is considered credible. This presents an opportunity for disseminating authoritative information about HIV. However, the possibility of spreading information privately, but widely, enhances the risk that confidential information will be shared and individuals will be stigmatized.
- One site reports that incest is a factor in transmission of HIV. While this is only a single report, incest is likely to be deeply hidden and should not be considered irrelevant if it does not come to light spontaneously, especially where other forms of family dysfunction are apparent.
- Another site reports an unexpected high level of awareness and concern about IPV in the study community.
- Finally, one site finds that careful monitoring of outreach and testing activities is vital to ensuring that services reach the intended high-risk populations.

The RARE method tends to encourage encounters with the unexpected. Grantees will profit, however, by asking how common their unexpected findings might be outside their study areas, why they have escaped attention previously, and how service providers can avoid being surprised in the future.

4. Conclusion

The RARE approach enabled grantees to identify a range of challenges that they must address to effectively reduce the spread of HIV in the populations they have targeted. One of the most valuable sets of challenges that grantees described centers on the fact that the high-risk behaviors described in detail above take place in a wide variety of fluid social arrangements and overlapping

networks. These arrangements and social networks link people who regularly engage in high-risk behaviors with people who do so only rarely, often without having any knowledge of the risks encountered. Another set of challenges facilitates and perpetuates high-risk behavior: Drug use and sexual activity overlap in complex ways to impair an individual's judgment regarding risk behavior, resulting in more unprotected sexual activity and high-risk drug use.

Lack of awareness of risk is a major challenge. However, some individuals appear to engage in denial and fatalistic thinking with regard to drug use and certain types of sexual activity. This unwillingness of some to view their behavior in terms of risk is a particularly challenging issue since such individuals do not appear to respond to conventional outreach methods focused on changing behavior through providing accurate information. Stigma, secrecy, and fear of public exposure also collectively discourage people who engage in high-risk behavior from seeking HIV testing, counseling, or substance abuse treatment.

On a broader level, other social factors, such as patriarchal relationships and Intimate Partner Violence, prevent some individuals who are at risk from successfully negotiating safer sexual encounters. Unaddressed, this can lead to the spread of HIV to those who do not view themselves at risk. Still further, grantees have recognized that there is considerable mistrust of public institutions, whose traditional approach to outreach and services has, in some cases, unintentionally perpetuated issues of stigma.

Grantees recognize that, to address these challenges, their organizations must enhance and expand services, and elicit the support of community leaders and institutions to combat stigma, promote awareness of risk behavior, and facilitate access to services. Religious institutions are viewed as having a potentially positive role to play, although many have yet to address the issue constructively. This expansion and promotion of community awareness must be tailored to the local community setting, and must be flexible enough to adapt to changing fluid social networks.

The RARE process provided grantees with a valuable opportunity to explore the dynamics of their populations while simultaneously building the necessary trust among those individuals who are often mistrustful of conventional systems of care. The creation of trust is vital in the effort to reduce stigma and for identifying the more fluid social and sexual networks that extend into typically low-risk populations.

IV.D. Summary of Grantee Recommendations

Grantees offer many recommendations regarding highly site-specific matters, such as designing educational messages to address the needs of a particular local group, including representatives of particular local populations, in planning and implementing outreach activities, clearing abandoned buildings in a particular neighborhood, or collaborating with particular local agencies and organizations. They also address what they perceive as specific emerging issues likely to be widely relevant. It is recommended, for example, that the growing importance of the Internet in sexual networking requires Internet-based strategies of HIV education, and that messages must be developed to counter the perceived implication of pharmaceutical advertising that new drugs take the worry out of HIV/AIDS.

There are also, however, broader themes running through grantee recommendations. Many grantees explicitly recommend various forms of *collaboration*, *integration*, and *inclusion* in initiatives to address HIV/AIDS in their cities and neighborhoods. One also can find these interlocking themes implied in a wider range of recommendations concerning using RARE in planning and implementing education and service provision.

Planning with RARE
Many grantees not only draw recommendations from their RARE findings but also endorse continuing to use the RARE method to investigate particular issues, such as "bridging behaviors" and "linking spots." It is more common, however, for grantees to recommend that current findings be shared with either particular local agencies or organizations (e.g., the County Board of Commissioners), or more widely (e.g., with all HIV and STD prevention initiatives or all local government bodies). Many such recommendations do explicitly state the purpose of such sharing, but others state that the point is to generally encourage use of the findings in either single-agency or collaborative planning and funding decisions.

Many grantees explicitly recommend collaboration among specific bodies or wider collaboration (such as by an "interagency task force") to plan HIV/AIDS initiatives. More often than not, grantees call for planning that is not only collaborative on the organizational level but also incorporates people from all sectors of the population, including "local experts" and members of affected populations. A number of grantees make special mention of the importance of including women in planning processes.

Collaboration, Narrow and Broad
Many grantees recommend carrying out education and service initiatives in collaboration with such specific partners as juvenile justice authorities and schools, to disseminate educational messages; local housing authorities, to demolish abandoned buildings that are sites for drug and sex trade; local

support agencies for individuals affected by IPV, to provide education and linkage to services; or bar and club owners, to facilitate onsite outreach work. A few grantees strongly recommend working with local medical providers to help them fashion approaches to providing HIV/AIDS services better suited to the nature and needs of particular populations. The importance of providing medical services in a nonjudgmental and compassionate manner is emphasized.

Recommendations for wider forms of collaboration are more common. Some grantees call for collaboration and coordination among all agencies receiving public funds to address HIV/AIDS; some call for coordination among all bodies providing prevention services; and some recommend establishing or strengthening broad community coalitions among all local bodies with a stake in addressing HIV/AIDS effectively.

Engaging with Religious Institutions

Several grantees recommend paying special attention to working closely with churches and other religious institutions. Churches are often identified as highly influential institutions, with potential to both strengthen and impede HIV/AIDS initiatives. Some grantees recommend simply including them in wider coalitions. Others, however, recommend not simply forging closer ties with churches, but also educating religious leaders on the nature of HIV so that churches can use their influence to address the stigma often attached to HIV.

Engaging with Law Enforcement

Grantees also often recommend giving special attention to collaboration with law enforcement. Some grantees see sex and drug trades, often important vectors of HIV infection, as part of a larger crime problem and recommend working with law enforcement agencies both to reduce crime in general and to discourage the sex and drug trades in particular. One grantee goes so far as to recommend working with law enforcement agencies and the health department to establish a policy of prosecuting anyone who knowingly spreads HIV infection.

Grantees, however, more commonly recommend working with police to facilitate prevention efforts. A number of grantees report that police in their areas interfere with promoting condom use and syringe exchange because they assume that possession of condoms is evidence of engagement in prostitution, and that syringe exchanges involve users of illegal drugs. Hence, these grantees recommend engaging with police to increase their understanding of such programs and recruit their cooperation. Similarly, one grantee recommends working with police to implement HIV education programs for people the police apprehend engaging in sex in public spaces.

Improving Education and Services through Community Engagement

The following are among the most common recommendations for improving education and service design and delivery.

- Use a harm reduction approach.
- Increase the quantity of certain services (e.g., opportunities for syringe exchange or HIV testing).
- Publicize available services better.
- Increase service quantity and information for specific target groups, such as migrant workers or women of childbearing age.
- Increase the number of hours of service availability.
- Make education and services available at central community locations, such as schools, workplaces (including agricultural sites), and popular gathering places or retail establishments.
- Make services available when and where risk behaviors occur, such as sites of drug and sex trade, recognizing that individuals who frequent such sites may be distrustful when approached.
- Involve members of the community known to and trusted by the at-risk population to provide or assist in providing education and other services.
- Improve confidentiality measures and cultivate greater trust between service providers and the target population.

Grantees often base the final recommendation on observation of the longstanding lack of trust between populations at risk and medical practitioners, researchers, and public health agencies.

Many grantees also recommend emphatically that education and services be provided in culturally competent and appropriate ways. Grantees' recommendations address not only the need for cultural competence regarding racial, ethnic, or linguistic minorities, but also of such groups as people over 50 years of age, people who are HIV positive, MSM who do not self-identify as gay, active sex workers, and drug dealers and users.

A favored approach to both addressing issues of trust and providing culturally competent education and services is to create more collaborative and inclusive programs. This can be done by engaging members of the target population in planning and implementing education and service activities, as peer educators, peer service providers, and peer navigators.

Integrating Services

Several grantees strongly recommend that HIV-related services be provided in the context of other health services, including substance abuse treatment and mental health services, and a wide range of social services, including food support, housing, job training, shelters for homeless or those affected by IPV, GED preparation, and employment assistance. The principal rationales for such a recommendation are:

- The need to efficiently address the full complement of health and social challenges associated with HIV, either as underlying causes or as consequences;
- The need to make HIV services more readily visible and available; and,
- The need to avoid the stigma often attached to those who use HIV-specific service sites.

A number of grantees stress the importance of addressing HIV among women in an integrated manner not only by recommending including women in planning and implementing HIV education and services, but also by arguing that to address HIV among women it is vital to recognize and address the social and cultural subordination of women, IPV and other violence against women, and women's economic dependence as aspects of the HIV issue.

Carrying Through

Several grantees point out the wisdom of building on existing initiatives rather than, as so many put it, "reinventing the wheel." A few also strongly recommended careful monitoring and evaluation of all initiatives from start to finish, including establishing baselines prior to beginning implementation. Evaluation is a key component of the full RARE process.

Most grantees do not address funding issues in their recommendations. A few do call for increasing funding for HIV/AIDS-related programs, identifying new sources of funding or agency/organizational collaboration in seeking additional funding.

Only a very few grantees identify specific entities as the logical implementers of specific recommendations. Many grantees do not indicate what body or organization they wish to carry out their recommendations. A number, however, do address their recommendations as a whole to a mayor, a particular city or county agency (most often the Public Health Department), or a collection of city and/or county agencies. A few identify the CWG, or a State or local HIV task force or planning group (including Ryan White CARE Act-mandated planning entities), and some specify that community leaders or the community in general are the audience for the recommendations. A few state the intention of presenting their recommendations to such entities or to "major funders." The extent to which grantees had, at the time of reporting, engaged in planning to pursue their recommendations or other further action is discussed in the following section.

IV.E. Other Results

Judging from the richness of grantees' reports and the scope and quality of their recommendations, the RARE process was well received. The process stimulated a great deal of thought, and they articulated interest in continuing

to use the RARE methods as part of local planning processes. Among one grantee's recommendations, for example, is a strong statement of the importance of institutionalizing the capacity to use the RARE process. Yet, only a very few grantees report that any local entity has formally adopted the method.

Among these, some give substance to their stated intentions by specifying the ways in which they expect to find RARE useful; for example, one grantee stresses the utility of the street intercept method for conducting continued needs assessments and environmental scans, and another states that RARE will be especially useful in understanding the homeless population better. No grantees, however, report explicitly that any resources have yet been committed to supporting continued use of RARE, although some express interest in fundraising to continue RARE subsequent steps in planning and implementing improvements to services based on the assessment findings.

More concrete results are reported with regard to creating and stimulating stakeholder networks. As described above, building and strengthening collaboration and cooperation among stakeholders is one of the most common themes in grantees' recommendations. A modest minority of grantees also reports actual steps toward that goal. Among these, the largest number cannot point to formation of specific formalized collaborative or cooperative relationships. Rather, they observe that the RARE process provided community entities something around which to coalesce, brought community members into closer contact with other stakeholders, or led to the growth of new informal coalitions or linkages among stakeholders.

A very few, however, report that more concrete institutional links were formed. For example, in one city the RARE leadership group has joined an existing domestic violence task force, and another site reports that RARE resulted in new forms of collaboration among branches of the city government. Yet, while few such concrete results are reported, it is clear that in a number of sites, using RARE has at least nurtured the potential for the kinds of collaboration most grantees see as necessary for more effective action against HIV/AIDS.

IV.F. Planning

Most grantees did not have the opportunity to develop planning processes within the RARE Program funding timeframe. Many emphasized that the local RARE Project findings should be incorporated into local planning and implementation processes. While most did not explicitly discuss planning processes, their recommendation sections implicitly suggested that the RARE findings would be incorporated in planning. Most of these grantees were in Cohort 1, and as such, represented local public health administrations. As a

result, due to their proximity to decision-makers, they are most likely to be in a position to incorporate findings directly into local planning processes. The CBOs funded in Cohort 1 also strongly recommended that their findings be incorporated into planning, specifically to address recommended changes in outreach related to local shifts in the epidemic.

Many grantees, particularly those in Cohort 2, did discuss next steps, such as those following, to ensure incorporation of their findings into the local planning process:

❑ Bringing the results of the RARE project back to the community;
❑ Printing and disseminating the final report and a press kit; and
❑ Holding meetings in the community to disseminate findings.

Many Cohort 2 grantees plan to market their RARE assessment results to local Public Health officials, Ryan White CARE Act Planning Councils, and other community stakeholders to inform the local planning process with locally relevant data on communities that have perhaps the highest level of need for services.

Several groups also noted that they intend to use the findings from the RARE project to develop educational materials that are appropriate for the community. And, several groups noted that the CWGs would continue to play a role in developing materials and disseminating information. However, while several groups noted their intentions of using the RARE findings, descriptions of planning processes lacked the detail and specific timelines that facilitate implementation.

IV.G. Grantee Challenges

The grantees identified specific challenges to implementing the local RARE Project in two areas: identifying and recruiting project partners, and data gathering. These challenges largely centered on networking issues and issues related to scheduling and timing.

Challenges Faced in Identifying and Recruiting Project Partners
Most grantees did not report any challenges in identifying and recruiting collaborators or members of their CWG. Some organizations did report challenges in identifying and recruiting participants for such reasons as scheduling conflicts; lack of people to interview as potential members; or the inability of the RARE team to successfully engage certain policymakers, public health agencies, or representatives from the faith-based community.

In certain cases, traditional public health partners were unwilling or unable to participate in the local RARE Project. Local community leaders and others who

were highly respected in the community were recruited to network into the community to identify participants.

Conversely, a lack of rapport within the community of interest could hinder grantees from recruiting cultural experts. Networking into the community was cited as a key determinant of success in implementing RARE. Working with other organizations or providers that serve the community can provide an entrée into the community for networking purposes.

Lastly, one grantee commented on the effect of agencies competing for information and funding. Because many local public health agencies are competing for the same Federal funding, there is a lack of interagency interest in sharing information that could place one agency at an advantage for limited resources.

Some grantees did note that, once recruited, scheduling conflicts often limited participation in CWG meetings and other RARE activities. Ensuring that certain key stakeholders were available to meet and assist in material review was cited as a central concern in conducting their RARE assessments.

Challenges Faced in Data Gathering

There was a variety of challenges faced by grantees in the data collection process, including issues of recruitment, scheduling, and lack of sufficient project time. The major recruitment challenge faced by RARE Field Team members was scheduling key informant interviews, cultural expert interviews, and focus groups.

Many healthcare providers in the communities of interest did not have sufficient time to participate in interviews and focus groups. Scheduling such activities outside of clinic hours enhanced availability of providers for participation. Commitments from community leaders and public officials were often difficult to come by, as well. Some public officials were in the process of campaigning and did not have time to schedule interviews or participate in focus groups, and others lacked enough interest in the issue at hand to garner participation. Grantees often asked staff members of public officials to serve as proxy participants.

Some healthcare providers who did not provide HIV/AIDS services but were knowledgeable of the community did not understand why they were asked to participate. Lack of understanding of the local RARE Project goals also hampered efforts to engage community members and cultural experts. Clearly articulating the goals of the effort and the value of their participation to the community enhanced their willingness to participate. Scheduling challenges were overcome in some cases through promoting the importance of the local RARE Project by CWG or Field Team members who were particularly well connected to potential participants.

In other cases, appropriate cultural experts or members of the community were unintentionally left out of the study as they were difficult to identify. Working through networks of community members and providers who serve particularly marginal populations increased the likelihood of their participation. In addition, some cultural experts could be identified only through street intercepts late at night, presenting significant scheduling burdens on the Field Team and raising issues of schedule flexibility and safety concerns. Safety of the Field Team members while working was addressed by developing safety protocols that stressed working as teams and keeping lines of communication open with both other project staff and law enforcement.

Inclement weather, particularly in winter months, affected some grantees in scheduling interviews or focus groups, particularly with drug users and sex workers, who could only be contacted through street intercepts. In some cases, scheduling venues for focus groups presented challenges related to seasonal events that reserved appropriate local venues in advance.

In some cases, individuals approached for street intercept surveys expressed suspicion or even hostility to the Field Team worker because of concerns over whether they represented a local law enforcement authority. In one case, people had participated in similar studies in the past without seeing any demonstrable benefits to themselves or their community. In other cases, confidentiality was a concern. However, hostility was mediated by RARE Field Team members taking time to talk with potential participants to hear and address their concerns. Confidentiality concerns were typically addressed by explaining that recorded interviews were for accuracy purposes only and no identifiers would be used.

Several grantees reported that there was not enough time allotted for the overall RARE data collection and analysis process to take place. From the outset, RARE Field Team members were challenged to accommodate the tight timeline of the RARE data collection and analysis process. Time and resource availability to appropriately and effectively analyze collected data was a particular challenge. Grantees reported that they lacked staff for transcribing or available resources to hire a transcriber to yield a complete set of data. As a result, only a small sample of interviews was transcribed and analyzed. In a few cases, tape recording equipment used for the interviews and focus groups was not of good quality, and produced inaudible or incomplete recordings. When RARE Field Team members were ready to listen to them, the recordings were unusable.

Several grantees included members of the communities of interest on the Field Team. However, community members were not familiar with data collection and analysis, so they required additional time for training in field methods. These grantees reported that a balance must be achieved between the value of

using community members as Field Team members to enhance trust and provide valuable insight into the community as a whole, and the need to ensure that data collected were valid and reliable. Teaming community members with other Field Team members more experienced in fieldwork was an important means of ensuring data reliability while gaining the insight and entrée of the community member.

The Challenge of Timing in a Rapid Assessment

Overall, most challenges faced by grantees in data collection were the result of the limited timeframe inherent in any rapid assessment process. Many reported that they did not fully understand the limitations that this would impose and would have benefited from an earlier start in hiring staff and recruiting individuals as project partners and as participants in the field research itself.

Rapid assessments are valuable in that they produce locally relevant data reflecting the current conditions that affect the spread of HIV in a population. However, rapid assessments must balance the value of data timeliness with the challenges imposed by the short timeframe. Most grantees reported that they relied on flexible scheduling and staff dedication to complete the RARE assessment, but that they would have preferred additional time from initiation to reporting to ensure that their assessment was complete.

V. Implications of Grantee Reports for the RARE Method

Grantees' reports on common challenges and lessons learned and their recommendations for others using the RARE method identify an inherent tension in the RARE method between the value of including diverse segments of the community in all phases of the RARE process and the value of quickly obtaining quality data on often overlooked aspects of the local dynamics of HIV/AIDS. Inclusion can pave the way to otherwise inaccessible data and help mobilize longer-term community involvement, but it also presents obstacles to obtaining quality data rapidly.

A significant majority of the challenges and recommendations grantees identified regarding forming RARE collaborations and gathering RARE data pertain to aspects of inclusion. For example, as discussed above, some grantees report difficulties in recruiting collaborators because providers, community leaders, and public officials are reluctant to make the time to participate, and members of marginal sectors of the community are suspicious of the RARE enterprise and RARE personnel. Many grantees also encountered exactly the same challenges when gathering data.

It is not surprising, then, that a large majority of grantees' recommendations stress the importance of involving community members from every sector, including religious leaders, experts (on HIV, IPV, and other specific topics), local activists, local officials, members of at-risk groups, and populations requiring specially tailored forms of outreach or communication, such as the hearing impaired. Grantees point out that such inclusion facilitates obtaining basic local knowledge, forging data gathering networks, and laying the groundwork for future community involvement and action.

Numbers of grantees also report that the limited amount of time available for the RARE assessment process—a maximum of four months—is a significant challenge. Some of the additional challenges noted are of a kind that might affect any enterprise, such as the difficulties that ensue if basic support services (transcription, data processing, administration) and funding are not in place at the outset. Limited time, however, poses special challenges for a research team recruited more with inclusion than with experience and expertise in mind. Community members do provide invaluable knowledge of local circumstances and networks, but they usually have no experience putting this expertise to use in the service of research. Hence, time is needed to train field investigators and implement ongoing data quality-control measures tailored to the nature of the local research team. Some grantees recommend strongly that others undertaking RARE institute continuous monitoring of data quality and adherence to the project schedule.

Of course, including members of the study population in the research team has advantages other than providing access to local knowledge and networks. It is also a way of encouraging community members to become invested in longer-term local mobilization against HIV/AIDS. But, as one grantee argues, doing this seriously requires their inclusion in reviewing and analyzing data, as well as in collecting it. Some grantees report that they do just this. However, it can take time to do it well.

One grantee's recommendation sums up concisely this dilemma of simultaneously pursuing inclusion and rapid research.

> If investment by the target population is the primary objective, more time should be allowed for inexperienced field members from the target population to collect data, have it transcribed, reviewed and analyzed collectively as a team process . . . . Yet, if time is the primary objective, it is recommended to hire an ethnographer/evaluator to carry out and analyze all the ethnographic work. Field Team members would be employed specifically to serve as recruiters for members of the target population willing to be involved in interviews and focus groups. Currently, the RARE project implies that both target population investment and rapid assessment objectives are critical, but does not allow the time or resources to produce excellent results for either objective.

This grantee clearly found the tension between the two dimensions of RARE frustrating. Nevertheless, resolving the tension by substantially subordinating either of RARE's two major aims would also rob the method of its potential for advances in understanding and addressing HIV/AIDS. The point, however, is not to resolve this tension but to manage it in order to reap the greatest benefits of the RARE method. Such management has two dimensions:

- Explicit discussion of the need to balance these two RARE imperatives in RARE training; and, as grantees have suggested,
- Continuous monitoring of data quality and project schedules within local RARE teams, emphasizing the need to manage potential conflict between aspects of the RARE method.

Ideally, such measures could help RARE implementers not merely to manage the tension in the RARE method, but in doing so, to realize more of the method's potential.

VI. Conclusion: Implications from the RARE Findings

The findings from the local RARE Projects have considerable implications for helping communities build capacities and develop effective strategies for assessing, planning, and implementing new or improved HIV/AIDS services. This section synthesizes common findings and states their implications for local efforts, as well as for broader policy. These implications are divided into different areas that communities can explore more deeply to develop strategies for addressing challenges and barriers.

Structural Factors Affecting Access to Care

It was evident from the grantees' findings and recommendations that fragmented and nonexistent services create barriers to information, testing, and care for many populations and individuals. Moreover, those gaps in service often pose particularly serious barriers for members of hard-to-reach communities.

Policy and programmatic implications related to structural access to services reflected in the RARE grantee reports include the following.

- Fragmentation interrupts and often prevents systematic care. For example, free-standing HIV testing sites may neither provide nor link to follow-on monitoring and treatment, when needed. More interagency collaboration could offer an efficient and effective network of services.
- Collaborative planning and coordination efforts on the part of service providers, including input from all stakeholders, could help define and promote linkages among providers and other stakeholders, and help them recognize and begin to address gaps.
- Reports indicate people are often unaware of the location of services, even when services do exist locally. Where services exist, they are often not sufficient or have inconvenient hours of operation for the population. In addition to capacity building at the community level, programs could emphasize the marketing and advertising of their services.
- Maps, as well as publication of locally available or alternative area services, locations, hours in which services are available, any costs, and access to transportation, could improve access. Information could be provided to both potential clients and service providers. Locating services near public transit would also improve access.
- Colocating services could assist in facilitating structural and geographic access. Where possible, the following could be colocated with or near health clinics or community health centers: employment services, further education enrollment and GED services, drug rehabilitation services, syringe exchange programs, and other health and social services.

- Services that require out-of-pocket payment by clients build in a potential barrier to testing and care. No-cost testing could eliminate a common barrier to accessing HIV and AIDS care.
- Client- and community-friendly staff encourage care access. Peer navigators could provide access to social service and other systems. Members of the local community could be used to staff services or as volunteers.
- Soliciting advice from clients regarding what services are missing, are not known to be available, or are difficult to reach could inform planning regarding service expansion and locations.
- Eliminating unnecessary duplication of services, which is costly and promotes competition among providers while leaving service gaps, could create new provider opportunities and provide a wider array of services.

Cultural Factors Affecting Access to HIV/AIDS Services

Policies and programs should reinforce the importance of culturally accessible care, including language access and providers who have cultural competence relative to the community. Information must be culturally accessible if it is to be effective in communicating essential information within a community. For example, providing non-English-speaking refugee populations with materials in their native languages improves access and builds trust in the community, as opposed to further isolating them from certain service sectors.

Access to HIV/AIDS Education and Information

Policies and programs could improve by identifying how consumers perceive bias and determining whether systematic bias has created barriers to those seeking information and services. Perception of bias is widespread. Some women and minorities believe that major public health agencies do not care about them. Hence, they believe that those agencies have lost interest in the epidemic as it has become concentrated among women and minorities. A reintensification and redirection of HIV/AIDS education and information initiatives that clearly target those populations could address this issue directly.

As part of this reintensification, programs should provide general and broad-based education that does not assume people and communities (including providers) have knowledge of the fundamentals of HIV/AIDS prevention. A corollary of this reintensification is that care must be easily and continuously available and that new and updated information must be disseminated regularly.

Misinformation is common. Grantees noted that policymakers, providers, stakeholders, and consumers need improved understanding of the disease and how it is affecting their community. Providers also need ongoing access to refresher and new information.

Stigma and Discrimination

The nature and extent of stigma and discrimination relative to HIV/AIDS differs by population, social perspectives cultural beliefs, and the relative availability of correct, culturally competent materials about HIV/AIDS. Awareness and understanding of the origins and depth of HIV/AIDS stigma and discrimination in a given community can help planners effectively address it.

Reinforcing confidentiality of care by providing testing, monitoring, and treatment services in integrated care settings, as opposed to freestanding test sites or HIV/AIDS care-specific sites, could also help reduce stigma. For many, seeking care at a general health clinic is less stigmatizing than entering an HIV/AIDS specialty clinic. City, county, and other public care facilities that often serve underserved and hard-to-serve populations should promote and display continuous awareness of community sensitivity to confidentiality of services.

Denial or fatalism

Stigma and discrimination interact with other psychosocial barriers, such as denial or fatalism. The belief that others do not care, or that a person will experience discrimination, makes it easier for the person at risk to avoid seeking care and to deny that their behavior entails risk. In populations of drug users, sex workers, and MSM who seek out anonymous sex, grantees observed that some clients are "in a state of denial" or have just given up trying to protect themselves. This unwillingness to receive the conventional public health messages is an aspect of the more widely discussed phenomenon of "message fatigue" and requires innovative responses that seek to assertively reach consumers while providing them with real options.

Women's Health

Women are at particular risk of HIV infection because socially and culturally defined and reinforced gender roles commonly allocate less control and power to them in male-female interaction and relationships. Related social and economic dependency makes it difficult for women to challenge male authority. This extends to control of sexual behavior and choices to reduce risk of HIV infection, particularly when women are affected by IPV. Grantees noted that in communities in which women have little realistic control over their own sexual behavior, promoting abstinence, for example, may have little effect.

Other factors affect women's access to services and information. Limited educational and economic opportunities for women can result in women engaging in transactional sex to meet basic economic needs. Cultural roles and socialization that emphasize women's powerlessness can further promote a fatalistic view of life. The development of materials and strategies that address women's real experiences and utilize alternative, but culturally competent views of women could improve access for these populations.

Providing HIV services, particularly education and testing, through other social service providers, especially for those affected by IPV, could more effectively reach women who might otherwise have no contact with HIV-specific service providers. In addition, policies and programs that address the particular needs of women regarding HIV risk, and access to care and treatment, can help reach youth and other family members.

Other Target Populations

Policies and programs must be tailored to the particular needs of specific populations at risk within hard-to-serve populations. The homeless population and older adults are two populations requiring attention that are highlighted by grantees.

Homeless men and women are seen as being particularly vulnerable to risk behaviors as they may exchange in sex for money, drugs, or shelter, while lacking the resources to engage in safer sexual practices. Policies and programs that promote education, including GED programs, volunteer experience, and links to employment, are central to prevention and amelioration of homelessness and related health risks, including HIV. Improving access to appropriate behavioral health services could help address the needs of that segment of the homeless population that suffers from co-occurring disorders.

Older adults often believe incorrectly that HIV is a condition affecting youth rather than persons of any age engaging in risk behaviors. Policies and programs must address the particular needs for HIV/AIDS awareness and education among older adults.

Religious Institutions

Many grantees stressed that religious institutions may have significant potential to facilitate HIV/AIDS-related education, enhanced awareness, testing, and care. However, religious institutions are also sometimes responsible for perpetuating stigma. Collaborating with religious institutions to help them provide accurate information and community support to address HIV/AIDS could help reduce stigma and build community trust. Religious institutions may be well-positioned to reach particular segments of hard-to-reach populations through other outreach activity.

Community Mobilization

Grantees' findings suggest that development of community action is key to responding successfully to the HIV/AIDS epidemic. The most effective initiatives typically have roots and ownership in the community itself. Organizations that are viewed as being outsiders, or whose staff do not reflect the diversity of the communities they are serving, will face challenges in those communities that are distrustful of outsiders.

International Perspectives and Immigrant Populations

The growing body of international research and documentation reporting on effectiveness of HIV/AIDS policy and programs in other nations can inform efforts to combat HIV/AIDS in the United States. This may be particularly true regarding efforts supporting immigrant populations in the United States.

Immigrants encounter new and often radically different social and cultural environments. The general vulnerability of newcomers puts them at potential risk for a variety of difficulties, including health risks. International research that focuses on refugee populations, refugees residing in camps, and the issues facing areas of high conflict can provide insight into the kinds of stresses that new immigrant populations are experiencing.

Conclusion

The findings from RARE projects have the virtue of being both highly contextual and, with the right analytical tools, potentially generalizable. Triangulating different types of data, and using community experts to collect those data, enables organizations to understand how their efforts can improve at the community level. At the same time, the RARE process encourages organizations to situate their efforts within a broader socioeconomic environment, and to compare and contrast their efforts with those of others who are providing HIV/AIDS services. This process of comparing and contrasting may also inform policymaking. The different implications described above are not exhaustive or definitive. However, they do provide evidence that with the proper kind of support, local organizations can effectively assess local challenges in the HIV/AIDS epidemic. Further community assessment projects, such as RARE, have the potential to continue to enrich findings and refine policy implications. Ideally, researchers will be able to use these findings to develop more standardized strategies. However, while HIV/AIDS is a global epidemic that requires a global response, the provision of HIV/AIDS services, like most of health care, will remain a local affair.

APPENDIX A:
Cohort 2 Final Report Guidance

GUIDANCE FOR REPORTING
Rapid Assessment, Response, and Evaluation (RARE)
Project Grantee Final Report

This guidance provides a structure for reporting on your RARE activities. Please use this guidance to produce your final report on your activities, successes, challenges faced, the ways you overcame those challenges, and the lessons you learned. This guidance provides topics to cover and questions to answer regarding each topic, and suggests items to attach to your report as appendices to illustrate your RARE activities. If you have additional topics that will help to illustrate your work, please add them to your report. You do not need to include in appendices complete sets of meeting records, research instruments, or all your raw data, for example, but only samples to help us understand your work better. Please do include any materials that you consider important to illustrate your efforts within your community. Recommended length of the report: 20–25 pages, not including title page and appendices.

1. **TITLE PAGE** Please include the name of the organization, date of submission, address of service operations, and contact information.

2. **TABLE OF CONTENTS**

3. **EXECUTIVE SUMMARY** In approximately 2 pages please summarize the main points of sections 4 through 10 of your report.

4. **ASSESSMENT METHODS**

- ☐ How did you identify stakeholders in your community? Please describe any challenges you encountered, and how you overcame them.

- ☐ Provide a list of participating stakeholders and their affiliations.

- ☐ Describe how you created your Community Work Group (CWG). Please describe any challenges you encountered, and how you overcame them.
  - ☐ Please include in the appendix samples of minutes or other records of meetings that illustrate issues addressed and decision making processes.

- ☐ Describe the Rapid Assessment(s) you have conducted: What issues did you assess, in what geographical areas, and with which population groups?

- ☐ What methods did you use to conduct RARE Rapid Assessments, such as focus groups, key informant interviews, informal conversations with community members, etc.? Please describe any challenges you encountered and how you overcame them.

□ Please provide in an appendix sample copies of focus group questions, interview questions, or other data collection guides or instruments.

5. ASSESSMENT RESULTS

□ What data/information did you collect?
 □ Please provide in an appendix sample summaries of interview or questionnaire results or other important kinds of data you collected, such as notes from informal discussions with community members.

□ What did you conclude from your data?

□ Did you learn anything new or unexpected; were there any unanticipated findings? If so, please describe them.

6. PLANNING METHODS

□ Have you planned or are you planning any rapid responses to issues identified by your RARE assessment(s)?

□ Describe your planning process: Who participated? When and where did planning activities take place? How were decisions made? Please describe any challenges you encountered and how you overcame them.
 □ Please include in an appendix samples of minutes or other records of planning activities that illustrate your planning process.

7. PLANNING RESULTS

□ Describe your action plan(s) and recommendations presented to the CWG, the Community Leaders, and Policymakers.

□ For each plan describe: What will it do? Who will implement it? When will you start? What outcomes do you expect? How will you document progress towards expected outcomes?

8. OTHER RESULTS

□ Has the RARE method for rapid assessments been adopted in your community, as a whole or in part, by different agencies/stakeholders? If so, please describe.

□ Has anyone committed resources toward continuing use of the RARE method? If yes, please describe.

☐ Has using the RARE method helped create new or enhance existing networks to address HIV or other issues in your community? If so, please describe.

9. TRAINING AND STAFFING

☐ Please describe the training in using the RARE method you received.

☐ Have the staff originally trained in the RARE method continued to work in your project?

☐ If staff originally trained in the method have left the project, has this affected the project's progress and effectiveness? If yes, please describe.

10. CONCLUSION

☐ Please summarize the principal lessons you learned through using the RARE method.

☐ Please describe any challenges you encountered that you have not already described in other sections of the report.

☐ Will you continue to use the RARE method?

☐ If you do not plan to continue using the method, please summarize your reasons.

☐ What would you recommend to others thinking about using the RARE method?